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The Personal Importance of Being Independent: Associations with Changes in Disability and Depressive Symptoms

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Abstract

Purpose/Objective—This study examined the role of independence centrality (the personal importance of being functionally independent) in adapting to functional disability in persons with spinal cord injury (SCI). We assessed how changes in disability related to changes in depressive symptoms, the association between independence centrality and depressive symptoms, and the role of independence centrality in moderating the association between changes in disability and changes in depressive symptoms.

Research method/Design—Using data from a randomized controlled trial (Schulz, Czaja, Lustig, Zdaniuk, Martire, & Perdomo, 2009) we focused on 173 SCI survivors who completed baseline and 12-month follow-up measures of independence centrality, disability (activities of daily living and instrumental activities of daily living needs), and depressive symptoms.

Results—Consistent with our predictions, increased disability was related to increased depressive symptoms, and higher independence centrality was associated with more depressive symptoms at baseline. Consistent with the lifespan theory of control, SCI survivors with high independence centrality experienced more depressive symptoms when disability increased but less depressive symptoms when disability decreased. SCI survivors low in independence centrality were less affected by changing levels of disability.

Conclusion/Implications—Persons with SCI with high in independence centrality have higher levels of depressive symptoms and are more responsive to changes in functional status. Given the

functional status trajectories of SCI survivors, having low independence centrality may be adaptive because it facilitates disengagement from unattainable goals.

Keywords

self-regulation; independence; spinal cord injury; disability

According to the life-span theory of control (Heckhausen & Schulz, 1993; Heckhausen, Wrosch, & Schulz, 2010; Schulz & Heckhausen, 1996), people are innately motivated to exert behavioral control over their environments in order to achieve important life goals. This involves manipulating the external world to fit one's needs and desires. However, there are circumstances in life such as age- illness- or accident-related changes in functioning that limit the ability to manipulate one's environment making some goals unattainable. Under these circumstances, disengaging from unattainable goals through cognitive processes that diminish their importance is an essential part of healthy functioning (Heckhausen, Wrosch, & Schulz, 2010; Wrosch, Scheier, Carver, & Schulz, 2003). For people with spinal cord injury (SCI) faced with long-term disability, deemphasizing the importance of physical functioning may be protective of their well-being (Schulz & Decker, 1985).

Research suggests that there are individual differences in the personal importance people place on functioning independently, or independence centrality, that impacts how people respond to receiving support from close others, as well as their own psychological and physical health (Martire, Stephens, Druley, & Wojno, 2002; Martire, Stephens, & Schulz, 2011). The aim of the present study was to better understand how independence centrality relates to adaptation to disability among people with SCI. Specifically, we examined how changes in disability relate to changes in depressive symptoms, how independence centrality relates to depressive symptoms, and how independence centrality affects the association between changes in disability and depressive symptoms.

Drawing from a large literature showing links between high levels of disability and depressive symptoms in a variety of populations (Lenze et al., 2001), we hypothesized that increased disability over time would be associated with increased depressive symptoms (Hypothesis 1). Next, we hypothesized that independence centrality would be positively associated with depressive symptoms. That is, the greater the importance of being independent, the higher the level of depressive symptoms in this sample of persons with long term disability (Hypothesis 2). Finally, we predicted that independence centrality would moderate the association between change in disability and change in depressive symptoms. Specifically, we expected that persons with high independence centrality would experience more depressive symptoms when disability increased and less depressive symptoms when disability decreased; whereas, persons low in independence centrality would be unaffected by changing levels of disability (Hypothesis 3).

Our hypotheses regarding independence centrality are in part based on past research with persons with osteoarthritis (OA) showing that individuals with a high level of independence centrality react negatively to receiving support from caregiving spouses and experience more depressive symptoms and less functionality, as measured by slower walk time (Martire, et. al., 2002; Martire, et. al., 2011). Our predictions are also consistent with the life

span theory of control which argues that under circumstances where primary control is limited because of injury, illness, or aging, individuals may benefit from adopting *secondary control* processes that diminish the importance of goals that are no longer attainable, such as independent physical functioning (Brandtstädter & Rothermund, 2002; Heckhausen et al., 2010). In this case, adopting secondary control means being more accepting of one's limitations and focusing on alternative goals that are attainable (Schulz & Decker, 1985). For persons with SCI, holding on to strong beliefs in independence centrality may be maladaptive because it emphasizes the attainment of goals that may not be within reach for the person with SCI.

Method

Participants and Procedure

Secondary data analysis was conducted using self-report measures from 173 SCI survivors who took part in a multisite, three-group, randomized controlled trial with their caregivers (see Schulz, et al., 2009 for caregiver characteristics). The purpose of the original study was to assess the efficacy of two psychosocial interventions for family caregivers of older persons with SCI.

Following a baseline assessment, SCI survivors and caregivers were randomly assigned to one of three conditions: a caregiver-only intervention condition; a dual-target intervention condition that targeted both the caregiver and SCI survivor; or an information-only control condition for caregivers only (see Schulz et al., 2009 for complete details). The caregiver-only intervention condition was designed to provide caregivers with strategies to reduce stress, improve health and self-care, enhance access to formal and informal support, and improve emotional well-being. The intervention was tailored to meet the specific needs of the individual using risk profiles obtained at baseline. All caregivers received standard information on all topics, but the emphasis on a particular topic varied as a function of the needs of the caregiver. The intervention was delivered over a 6-month period and consisted of seven 60- to 90-min individual sessions at home (five sessions) or by telephone (two sessions) and five structured telephone-based support group sessions. The individual with the SCI was not targeted in this condition.

The dual-target intervention condition targeted both the caregiver and the individual with SCI. The caregiver component intervention was identical to that of the caregiver-only condition, and the topics, procedures, and intervention strategies used with the caregiver were adapted for the care recipient. In addition, care recipients were taught about the potential impact of providing care to someone with SCI on the health and well-being of the caregiver.

Caregivers who were randomly assigned to the control condition received the same standardized packet of written information on SCI, the aging process, community resources and programs, and caregiving as participants randomly assigned to the active intervention conditions. The individual with the SCI was not targeted in this condition.

All participants were assessed at home by certified assessors at 6 and 12 months after baseline. Assessors were blind to treatment condition at the follow-up assessments. In the present study we focus on assessments at baseline (Time 1) and 12 months (Time 3).

Of the 173 SCI survivors, 87% ($n=151$) completed a 12-month follow-up. The results of the original study were that caregivers in the dual-target condition had improved quality of life at 12 months. There were no statistically significant differences in dropout rates across the three groups. No significant differences were found between those who completed the study and those who did not in terms of demographic characteristics, baseline independence centrality, or depressive symptoms.

The complete sample of SCI survivors was predominantly white men (65%) with a median age of 54 ($range=30-84$). Seventy-three percent of survivors had a high school education or higher. The location of SCI was lumbar (5%, with 11% complete lesions), thoracic (30%, with 53% complete lesions), or cervical (51% with complete lesions)¹. Time since injury varied from 1 to 63 years with a median duration of 8 years.

Measures

Demographic information—Standard demographic data were collected on all participants: age, education, race, gender, and location of SCI.

Depressive symptoms—SCI survivors completed a 10-item version of the Center for Epidemiological Studies Depression Scale (CESD; Irwin, Artin, & Oxman, 1999; Radloff, 1977). This scale assessed the depressive symptoms of participants using the previous week as a reference. Participants were asked the extent to which they agreed with statements like, “During the past seven days, I was bothered by things that don’t usually bother me” and “During the past seven days, I felt lonely.” Participants rated each item using a Likert scale which ranged from 0 (*experience rarely or none of the time*) to 3 (*experience most or all of the time*). Possible scores ranged from 0-30, with higher scores indicating greater depressive symptoms. A score of 8 or higher is widely interpreted as being at risk for clinical depression (Irwin, et al., 1999). Cronbach’s alpha was .76. Table 1 shows means and standard deviations for depressive symptoms and other study variables.

Independence centrality—The Independence Centrality scale assessed the personal importance survivors placed on being functionally independent and being able to carry out “daily living activities” (Martire et al., 2002). This 7-item scale was based on theoretical and empirical work on identity and social support (e.g., Nadler, 1997; Ryan & Solky, 1996) which suggest three dimensions of this construct: the personal value of various domains to an individual’s identity, behaviors related to seeking support to highly central tasks, and the emotional aspect of receiving help with those tasks. This scale was developed by Martire and colleagues, has been validated and used in multiple, existing investigations (Martire et al., 2002; Martire et al., 2011).

¹The higher the lesion (e.g. Cervical-neck area) the worse for the patient. A complete cervical lesion would result in quadriplegia, as would an incomplete one. Thoracic is next level down, followed by lumbar. The latter two categories would typically lead to paraplegia, with control of arms and hands maintained. Level of lesion (complete vs. not complete) was not significantly associated with any of the study variables.

Participants were asked to indicate the extent to which they agreed with statements like, “Being able to do these activities (daily activities of living) on your own is very important to you” and “Sometimes you won’t even ask for help with these activities, even if doing these activities by yourself is difficult or painful.” Responses were in the form of a Likert Scale which ranged from 1 (*Strongly Disagree*) to 4 (*Strongly Agree*). Scores could range from 7 to 28. The Cronbach’s alpha was .71.

Disability/ basic (ADL) and instrumental (IADL) activities of daily living needs

—Survivors were asked whether or not they needed any kind of help with 15 ADLs (e.g., help with feeding, bathing, grooming, respiration problems, bladder problems) and 8 IADLs (e.g. laundry, housekeeping, food preparation, help with finances) during the past week (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963; Lawton & Brody, 1969). Participants indicated “yes” (1) or “no” (0) for whether they needed help with each activity. Sum scores were used.

Analysis Plan

We first characterized the sample in terms of independence centrality, disability (ADL and IADL needs separately), and depressive symptoms at Time 1 and Time 3 by calculating the means at each time point and the change scores between time points. We then conducted paired t-tests to examine the significance of changes over time. We also report the proportion of individuals who indicated decreases, no change, and increases in independence centrality, disability, and depressive symptoms over time (see Table 1). All analysis were performed with an aggregated sample of SCI survivors from the three intervention groups². In addition, we examined whether these variables (baseline and change scores) significantly differed among the intervention groups using ANOVAs.

Next, to identify covariates, we examined correlations between the demographic variables and baseline disability, depressive symptoms, independence centrality, change in disability, and change in depressive symptoms. As shown in Table 2, baseline centrality of independence was significantly associated with gender, such that women had higher levels of independence centrality than men. Centrality of independence was also significantly associated with greater depressive symptoms at baseline.

To test each hypothesis, we ran regression models (separately for ADL and IADL needs). Independent variables were centered on the group mean. For the models testing Hypothesis 1, change in disability was entered predicting change in depressive symptoms. For the model testing Hypothesis 2, baseline independence centrality and gender were entered predicting baseline depressive symptoms. For the models testing Hypothesis 3, baseline independence centrality, change in disability, and gender were entered in Step 1, and the interaction term (independence centrality *disability change) was entered in Step 2 predicting change in depressive symptoms. To further examine the nature of significant interactions we followed the guidelines of Aiken and West (1991) plotting the association between change in

²We ran our aggregate models with and without entering intervention group (either intervention group=0 and control group=1) as a covariate. Entering this variable did not significantly affect our findings, so we present the simplified model.

disability at 1 standard deviation above and below the mean of baseline independence centrality. We also tested the significance of each simple slope. Finally, we conducted stratified analyses testing whether the associations differed among the intervention groups. This consisted of running separate models for each intervention group.

Results

Changes in disability and depressive symptoms and their association (Hypothesis 1)

As shown in Table 1, independence centrality and depressive symptoms did not significantly change over time. However, ADL needs decreased significantly over time for the overall sample, indicating increased functionality for the overall sample of SCI survivors. Nearly half of individuals (44%) experienced decreased ADL needs over the 12-month period; whereas, 26.5% had increased and 29.1% had the same level of ADL needs.

As hypothesized, increased ADL needs were significantly associated with increased depressive symptoms ($B=.41$, $SE=.18$, $\beta=.18$, $t(150)=2.23$, $p<.05$; $R^2=.03$). Stratified analysis by intervention condition revealed that the association between change in ADL needs and depressive symptoms was significant only in the control condition ($B=1.46$, $SE=.38$, $\beta=.46$, $t(55)=3.81$, $p<.001$; $R^2=.21$).

IADL needs did not change significantly over time, and there were no significant associations between IADL needs and depressive symptoms ($B=-.08$, $SE=.21$, $\beta=-.03$, $t(150)=-.38$, ns ; $R^2=.00$). Stratified analysis by intervention condition also did not reveal any significant associations.

Association between independence centrality and depressive symptoms (Hypothesis 2)

As hypothesized, baseline independence centrality controlling for gender was significantly associated with depressive symptoms, $\beta=.43$, $t(172)=6.09$, $p<.001$, $R^2=.20$. Stratified analyses by intervention condition did not change these results, nor did adding other covariates (age, years since injury, ADL needs and IADL needs) diminish the significance of independence centrality as a predictor of depressive symptoms.

Moderating effect of independence centrality on the association between change in disability and change in depressive symptoms (Hypothesis 3)

As shown in Table 3, and as hypothesized, there was a significant moderating effect of independence centrality on the association between change in ADL needs and depressive symptoms. Follow-up analyses revealed that for people with high baseline independence centrality, an increase in disability was associated with an increase in depressive symptoms over 12 months, $\beta=.69$, $SE=.24$, $\beta=.30$, $t(150)=2.92$, $p<.01$. For people with low baseline independence centrality, the association between change in disability and change in depressive symptoms was not significant, $\beta=-.06$, $SE=.29$, $\beta=-.03$, $t(150)=-.21$, $p=.84$. As shown in Figure 1, people with high independence centrality experienced decreased depressive symptoms with decreasing levels of ADL needs.

Stratified analysis by intervention condition revealed that the moderation effect was significant only in the control condition ($B=.26$, $SE=.10$, $\beta=.33$, $t(55)=2.65$, $p<.05$; R

squared= .42). There was no significant moderating effect of centrality of independence on the association between IADL needs and depressive symptoms ($\beta=.16$, $t(150)=1.35$, $p=.18$), and this was not modified by intervention condition.

Discussion

In this study we investigated whether change in disability related to change in depressive symptoms and how individual differences in SCI survivors' independence centrality influenced this association. We also examined whether independence centrality was associated with depressive symptoms at baseline. As predicted, we found that changes in ADL functioning were associated with changes in depression, and independence centrality moderated this association. Also as predicted, we found that independence centrality was associated with greater depressive symptoms. Importantly, these associations were most evident for SCI survivors who did not take part in an intervention to improve the well-being of a caregiver, suggesting increased generalizability of the findings to the broader SCI population.

First, increased disability, or increased ADL needs, was associated with greater depressive symptoms over time. This is a frequently reported finding in the aging literature overall, but little is known about fluctuations in disability and the implications of short-term fluctuations among persons with SCI, particularly in this age cohort and at this later stage of injury. In this study we found that most individuals with SCI reported decreases in ADL needs within a relatively short period of time, but not IADL needs. Improvements in ADL needs were found primarily in areas related to toileting. Interestingly, changes in ADL needs were not significantly related to how long participants had SCI. Also, we did not find cross-sectional associations between baseline disability and depression, suggesting that short term changes in disability may be more influential for mental health than stable, long-standing disability. Further research is needed to better understand the variability of disability among SCI survivors over time and its relation to depression.

As hypothesized, we also found that SCI survivors with high independence centrality responded differentially to changes in ADL needs such that increasing needs resulted in more symptoms of depression and decreasing needs in fewer symptoms of depression. In contrast, SCI survivors low in independence centrality showed little variability in response to changing levels of ADL needs. The increased sensitivity among SCI survivors with high levels of independence centrality is a double edged sword. When their ability to function independently improved, these SCI survivors experienced higher levels of well-being, but they were also more likely to experience lower levels of well-being when functional abilities moved in the opposite direction.

These findings beg the question, which of these two groups of SCI survivors are better adapted to their life circumstances? Viewed from the perspective of a life course theory of control, one might hypothesize that the emotional responsiveness of people with high independence centrality would serve as a motivational resource that encourages primary control striving. This would result in lower levels of disability and/or slower rates of decline in functioning when compared to people with low independence centrality. However, we

found no difference between people who are high and low in independence centrality in either baseline ADL needs or changes in ADL needs. We did find, however, that independence centrality was strongly associated with depression at baseline suggesting that holding onto strong beliefs about the importance of independence is maladaptive in a context where independent functioning is compromised. Thus, it may be adaptive for people to place importance on being independent as long as they are able to exert control over these life domains. Once the ability to maintain primary control over independent functioning declines, this mindset may not be adaptive. This adds support to the lifespan theory of control which proposes that disengaging from unattainable goals can enhance psychological functioning (Heckhausen & Schulz, 1993; Heckhausen, et al, 2010; Schulz & Heckhausen, 1996; Wrosch et al., 2003).

Although not a central aim of the study, we found that women in this sample reported greater independence centrality than men, which contradicts gender role theory. Gender role theory would suggest that women are more communally oriented, and men are more agentic, or oriented towards the self (Spence, 1984). However, it may be the case that having an SCI disrupts the gender role norms in close relationships, in which women help their partners with daily living activities more than men do (Miller & Cafasso, 1992). Thus, it may be particularly important to pay attention to how SCI-related disability affects depressive symptoms in women. Also, our findings regarding disability were limited to basic activities of daily living and not instrumental activities of living. It might be that basic activities of daily living are more threatening to one's need for independence than instrumental activities of daily living because they are more fundamental to the quality of life of older individuals.

A limitation of this study is that participants were only followed for 12 months. This short time-span may have limited our ability to capture more substantial changes in disability over time. Also, it is unclear whether or not the changes in disability that were found in the present study were clinically meaningful. Overall we found that ADL needs decreased about .44 out of 15 ADLs suggesting a fairly meaningful change. However, other methodological approaches, such as using cut scores, may improve the ability to detect clinically significant differences (Atkins, Bedics, McGlinchey, & Beauchaine, 2005; Jacobson & Traux, 1991). This issue of clinical significance also applies to changes in depressive symptoms and independence centrality. Secondly, we do not have information about peoples' feelings of independence centrality before they had an SCI or about specific secondary control strategies they use. It would be interesting to see whether having an SCI changes a person's desire to be independent and in what ways. It will also be important to ask more specifically about comfort (in addition to discomfort) in receiving support. Thirdly, there is a relative lack of granularity in the ADL measure. Moving from supervision to set-up in a task may not be as difficult for an individual as moving from moderate assistance to dependence. Future studies examining the granularity of ADL change would be informative. Finally, all participants took part in an intervention designed to improve the well-being of caregivers of SCI survivors. Thus, it is unclear if the changes in SCI survivors' disability and depressive symptoms found in this study were confounded by the intervention itself. It is possible that intervention-related changes in caregivers' well-being or other unmeasured variables related to the SCI survivors' well-being influenced SCI survivor's disability, depressive symptoms, or independence centrality after baseline. However, in the

present study we focused on an *intrapersonal* process—how a relatively stable personality characteristic of the SCI survivor related to his or her own adaptation to disability. Thus, we tested our hypotheses with the entire sample of SCI survivors to maximize power and generalizability. That being said, we did find that our significant results were driven by the control group, in which the caregiver received only written information about SCI and aging and SCI survivors were not involved at all. This indicates that the intervention groups may have mitigated some of these more naturally occurring processes and that our findings are applicable to the broader SCI population.

The results of our study have important clinical and research implications for understanding how SCI survivors and their caregivers cope with disability. First and foremost, it is important for caregivers to help maximize their partner's autonomy in as many domains as possible; however, balancing primary control-striving with secondary control strategies is essential for well-being. This may be particularly true for people who desire high levels of independence. This study also has implications for older adults coping with disability in general. Successful life course development requires that we shift from primary to secondary control strategies when goals are no longer attainable through primary control. It is also important for people to feel comfortable relying on their close relationship partners when support is needed. Dependence is an important part of close interpersonal relationships (Bowlby, 1969/1982), and knowing how to accept support can be just as important as knowing how to give support.

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Impact

- Although research has shown that increases in disability are often associated with increases in depressive symptoms, little is known about how individual differences influence this association. This is the first study to examine how individual differences in the personal importance of being functionally independent relate to depressive symptoms and how persons with SCI respond psychologically to changes in disability over time. In addition, this study focuses on older individuals with SCI several years post-injury. Most studies focus on the immediate post injury period.
- The study shows that persons with SCI who desire high levels of independence are at heightened risk for experiencing depressive symptoms.
- Interventions to assist persons with SCI and their family members should take into account individual differences in the desire for functional independence.

Figure 1.

Association between change in disability and depressive symptoms for survivors with low (1 sd below the mean) and high (1 sd above the mean) independence centrality

Table 1

Descriptive statistics of study variables

	T1 mean (SD)	T3 mean (SD)	T3-T1 mean (SD)	t(150)=	# of participants who increased (%)	# of participants who decreased (%)	# of participants who experienced no change (%)
Independence centrality	21.68 (3.57)	21.60 (3.47)	-.28 (3.48)	-.98	61 (40.4)	70 (46.4)	20 (13.2)
ADL needs	5.42 (3.90)	5.05 (4.03)	-.44 (2.25)	-2.37*	40 (26.5)	67 (44.4)	44 (29.1)
IADL needs	4.37 (2.16)	4.32 (2.35)	-.10 (1.99)	.61	46 (30.5)	57 (37.7)	48 (31.8)
Depressive symptoms	9.48 (5.89)	10.02 (6.24)	.33 (5.18)	.79	67 (44.4)	69 (46.7)	15 (9.9)

Note. T1= Time 1, T3= Time 3;

*
p<.05;

of participants who increased, decreased, or who experienced no change reflect changes in raw scores from T1 to T3

Table2

Inter-correlations between study variables

	1	2	3	4	5	6	7	8	9	10	11
T1											
1. Age	1	-.05	-.01	.04	-.02	.02	-.03	.12	.18*	.06	.10
2. Gender		1	.04	.00	-.10	-.14	-.21**	-.07	.02	-.03	-.03
3. Years from injury			1	-.11	-.11	.01	-.04	.00	-.02	.05	.10
4. ADL needs				1	.59**	.03	.01	-.23**	.07	.05	-.07
5. IADL needs					1	.08	.07	-.04	-.37**	.07	-.07
6. Depressive symptoms						1	.44**	-.20*	.02	-.38**	-.13
7. Independence centrality							1	-.09	-.01	-.13	-.51**
Change (T3-T1)											
8. ADL needs								1	.25**	.18*	.06
9. IADL needs									1	-.03	.03
10. Depressive symptoms										1	.23**
11. Independence centrality											1

Note. T1= Time 1, T3= Time 3,

*** p<.01,

* p<.05,

† p<.10

Table 3

Regression model predicting change in depressive symptoms

	B	SE	β
Intercept	1.22	1.50	
Gender	-.48	.88	-.05
T1 centrality	-.19	.12	-.13
ADL change	.31	.19	.13
T1 centrality X ADL change	.10*	.05	.16

*
 $p=.05$, $df=150$, R^2 for model with main effects only=.05, R^2 for model adding the interaction term=.07